



TITLE:

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OBSERVATIONAL STUDY

OPEN

A Cross-Cultural Study on Behaviors When Death Is Approaching in East Asian Countries

What Are the Physician-Perceived Common Beliefs and Practices?

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Abstract: The primary aim of this study was to explore common beliefs and practices when death is approaching in East-Asian countries.

A cross-sectional survey was performed involving palliative care physicians in Japan, Korea, and Taiwan. Measurement outcomes were physician-perceived frequencies of the following when patient death was approaching: (1) reluctance to take part in end-of-life discussions, (2) role of family members, (3) home death, and (4) circumstances surrounding death.

A total of 505, 211, and 207 responses were obtained from Japanese, Korea, and Taiwan physicians, respectively. While 50% of the Japanese physicians reported that they often or very often experienced families as being reluctant to discuss end-of-life issues, the corresponding figures were 59% in Korea and 70% in Taiwan. Two specific reasons to avoid end-of-life discussion, “bad things happen after you say them out loud” and “a bad life is better than a good death” were significantly more frequently observed in Taiwan. Prioritizing the oldest of the family in breaking bad news and having all family members present at the time of death were significantly more frequently observed in Korea and Taiwan. Half of Taiwanese physicians reported they often or very often experienced the patients/family wanted to go back home to die because the soul would not be able to return from the hospital. In all countries, more than 70% of the physicians reported certain family members were

expected to care for the patient at home. At the time of death, while no Japanese physicians stated that they often experienced patients wanted a religious person to visit, the corresponding figure in Korea and Taiwan was about 40%. Uncovered expression of emotion was significantly frequently observed in Korea and Taiwan, and 42% of the Japanese physicians reported family members cleaned the dead body of the patient themselves.

There seem to be significant intercountry differences in beliefs and practices when death is approaching in East Asian countries. Future studies on direct observations of patients and families are needed.

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Abbreviation: ANOVA = analysis of variance.

INTRODUCTION

An understanding of cultural differences is very important for providing patient- and family-centered end-of-life care. What patients and families believe is usual or appropriate when death is approaching is heavily influenced by culture, and to provide appropriate care for imminently dying patients, an understanding of the culture of the patients and family members is essential.^{1–4} Nonetheless, to the best of our knowledge, there have been no large-scale studies regarding what is usual when death is approaching, except for review articles based on the experience of clinicians. Existing cross-cultural studies have been focused on patient autonomy, information disclosure, communication, decision-making, hydration, pain management, and withdrawal/withholding of life sustaining treatments.^{5–12}

East Asia is traditionally regarded as a typical family-centered region that is based on Confucian culture.⁴ Japan, Korea, and Taiwan, however, have considerable differences in cultural traditions, and each country could have unique traditions about death and dying. For example, several studies indicated that, in Taiwan, families believe that the soul will not be able to return from the hospital if patients die in hospitals; this could have a great deal of influence on the patient-preferred place of death, that is, many Taiwanese want to go back home to die even if they are unconscious.^{4,13–15} In Korea, it is suggested that the concept of filial piety (devotion to and respect for parents) and strong ties among family members heavily influence end-of-life decisions.^{4,16–18} In Japan, many identify themselves as both Buddhist and Shinto; they do not attend worship services or participate in seasonal rituals for several occasions without religious aims.^{4,19–22} In these 3 countries, the situation is rapidly changing, and clarification of the common beliefs and practices in East Asian countries when death is approaching is valuable for the provision of culturally suitable end-of-life care.

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The primary aim of this study was to explore the potential differences in common beliefs and practices when death is approaching, based on physician reports from these East Asian countries.

METHODS

This was a cross-sectional survey of palliative care specialists in Japan, Korea, and Taiwan. Measurement outcomes were physician-perceived frequencies when patients were dying. There was also an assumption that rough estimates of the frequencies were not seriously different from direct observation of patients.

Subjects and Procedures

We distributed a questionnaire to palliative care physicians. Rationale for selecting palliative care physicians for this study is that physicians are reasonably reliable source of information without burden on patients and families. Furthermore, palliative care physicians as data sources was highly feasible, as they experienced many patient deaths and this proxy method is reliable and common in palliative care research.^{23,24} Due to differences in specialist registry and survey feasibility among the countries, we decided to adopt the most feasible methods based on the actual situation in each country. All the palliative care physicians in the three countries work in the hospitals.

In Japan, all 605 palliative care physicians certified by the Japanese Society of Palliative Medicine before June 2012 were recruited. Physicians' names and affiliations were obtained from the website of the Society, and questionnaires were distributed by mail with 2 reminders (a total of three). No reward was provided.

In Korea, due to the lack of a nationwide registry of palliative care physicians, questionnaires were distributed via 3 methods. One was 5-spot surveys at academic congresses or symposiums related to palliative medicine from October 2013 to January 2014, and a total of 97 responses were obtained. The second was an e-mail survey, and a total of 32 responses were obtained from a convenient sample of 110 palliative care physicians through a local network. The third was an additional hospital-based survey involving palliative care physicians working at 3 hospitals, and 82 responses were obtained. A small monetary reward was given for each response.

In Taiwan, all 578 palliative care physicians certified by the Taiwan Academy of Hospice Palliative Medicine before June 2012 were recruited. Physicians' e-mail addresses were obtained from the Academy, and questionnaires were distributed via e-mail with 2 reminders (a total of three). A small reward was given to each participant completing the survey.

In all countries, responses to the questionnaire were voluntary, and confidentiality was maintained throughout all investigations and analyses. No identification numbers were linked with the original data. The ethical and scientific validity were approved by institutional review boards in each country.

Measurements

For measurement outcomes, we decided to explore 4 areas: (1) reluctance to take part in end-of-life discussions, (2) role of family members, (3) home death, and (4) circumstances surrounding death. These measurement outcomes were developed based on a systematic literature review regarding this topic,¹⁻²² discussion among research groups, and preliminary in-depth

interviews. Face validity was confirmed by a pilot testing on 10 palliative care clinicians using qualitative format, and after several revisions all finally agreed questionnaires were understandable and appropriate in each country. The questionnaire was simultaneously developed in Japanese, Korean, Taiwanese, and English. For all questions, the physicians were asked to rate the frequencies they experienced them on a Likert scale of 1 (not at all), 1 (rarely), 2 (sometimes), 3 (often), to 4 (very often).

Reluctance to take part in end-of-life discussions was investigated using 3 items: (1) family members are reluctant to discuss end-of-life issues until the patient is at the terminal stage; (2) because "bad things happen after you say them out loud," the patient and family are reluctant to talk about a future worsening in the patient's condition; and (3) because "a bad life is better than a good death," the patient and family are reluctant to talk about a future worsening in the patient's condition.

The role of family members was investigated using 3 items: (1) when the physicians report "bad news," they speak to the oldest or head of the family first; (2) families recognize as important that all family members are present at the last moment; and (3) children want to do everything to fulfill "filial piety." These involve the core concepts of Confucianism, that is, respect for older persons and the family bond.

Home death was investigated using 5 items: (1) because it is believed that "the soul will not be able to return from the hospital," patients and their families want death to occur at home; (2) because "death at home brings bad luck," patients and their families do not want death to occur at home; (3) for the sake of "saving face," patients and their families do not want death to occur at home; (4) certain family members are expected to care for the patient; and (5) patients ask someone who is not their relative (eg, friend or neighbor) to take care of them instead of their family.

Circumstances surrounding death were examined using 4 items: (1) patients want a religious person to visit them during their terminal phase; (2) when the patient dies, family members, including men, do not hesitate to express emotions (eg, crying out); (3) family members clean the dead body of the patient themselves; and (4) family members bathe the patient after death. The last 2 were excluded in the Korean questionnaire because a pilot test revealed that these questions made no sense to Korean participants.

Statistical Analyses

To explore the frequencies of physician experience, we adopted 2 comparison methods. One was the analysis of variance (ANOVA) among the 3 countries; and another was comparing the frequencies of often or very often using Chi-square tests. Both analyses obtained the same results, so we decided to provide the results of the latter, that is, frequencies of the respondents who answered often or very often, for easier interpretation. We calculated 95% confidence intervals, and a *P*-value less than 0.01 was regarded as significant.

Specialty was categorized as internal medicine (general internal medicine, subspecialties of internal medicine, psychosomatic medicine, and family practice), surgery (surgery and related subspecialties, such as gynecology and otorhinolaryngology), anesthesiology (anesthesiology, pain medicine), and oncology (medical oncology, radiation oncology, and clinical oncology).

All analyses were performed using the Statistical Package for the Social Sciences (ver. 11.0) (Chicago, IL).

TABLE 1. Physicians' Characteristics

Characteristics	Korea (n = 211)	Japan (n = 505)	Taiwan (n = 207)	P
Sex				<0.001*
Male	105 (51%)	417 (83%)	138 (70%)	
Female	103 (49%)	85 (17%)	59 (30%)	
Specialty				<0.001*
Internal medicine	119 (57%)	147 (30%)	158 (80%)	
Surgery	19 (9.0%)	183 (37%)	4 (2.0%)	
Oncology	67 (32%)	52 (10%)	33 (17%)	
Anesthesiology	4 (1.9%)	116 (23%)	3 (1.5%)	
Clinical experience (mean years, standard deviation)	11.3 (8.3)	26.5 (7.5)	14.4 (8.9)	<0.001*
Working area				<0.001†
Urban	136 (65%)	273 (55%)	137 (69%)	
Rural	75 (36%)	228 (46%)	61 (31%)	

* Significant difference was observed in Japan versus Korea, Korea versus Taiwan, and Taiwan versus Japan ($P < 0.001$).

† Japan versus Korea ($P = 0.016$) and Taiwan versus Japan ($P < 0.001$).

RESULTS

A total of 505 and 207 responses (83% and 36%, respectively) were obtained from physicians recruited from Japan and Taiwan, respectively. In Korea, a total of 211 responses were obtained. Mean clinical experience of the physicians was more than 10 years in all countries (Table 1).

Reluctance to Take Part in End-of-Life Discussions

There was a similar trend in responses to reluctance to take part in end-of-life discussions from the 3 countries: Japan was the lowest, Korea was moderate, and Taiwan was the highest. While 50% of the Japanese physicians reported that they often or very often experienced reluctance on the part of family members to discuss end-of-life issues, the corresponding figures were 59% in Korea and 70% in Taiwan. Two specific reasons to avoid end-of-life discussion, "bad things happen after you say them out loud" and "a bad life is better than a good death" were most frequently observed in Taiwan, to a significant extent (Figure 1).

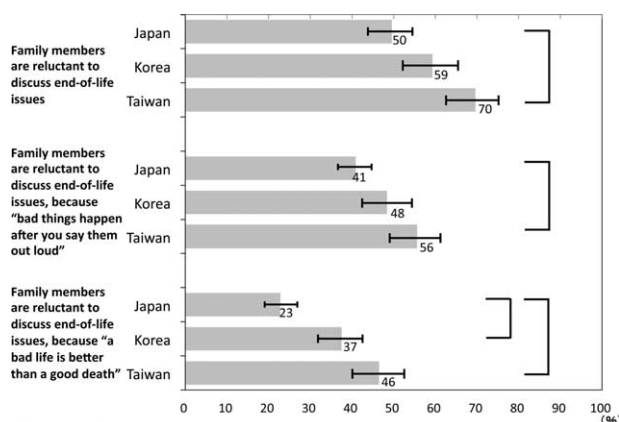


FIGURE 1. Reluctance about end-of-life discussions. * $P < 0.01$; bars demonstrate 95% confidence intervals.

Role of Family Members

Prioritizing the oldest or head of the family to break bad news and all family members being present at the time of death were significantly more frequently observed in Korea and Taiwan than in Japan, without a statistically significant difference between Korea and Taiwan. More than 60% of Korean and Taiwanese physicians reported they often or very often found that bad news was given to the oldest or head of the family first, while only 16% of Japanese physicians reported a similar situation. More than 80% of Korean and Taiwanese physicians reported they often or very often experienced that the presence of all family members was regarded as important, while 50% of Japanese physicians reported a similar situation. With regard to the concept of filial piety, there was a significant trend of Japan being the lowest, Korea moderate, and Taiwan having the highest regard (Figure 2).

Home Death

As a reason for wanting home death, half of Taiwanese physicians reported they often or very often experienced that patients/family wanted the patient to die at home because the

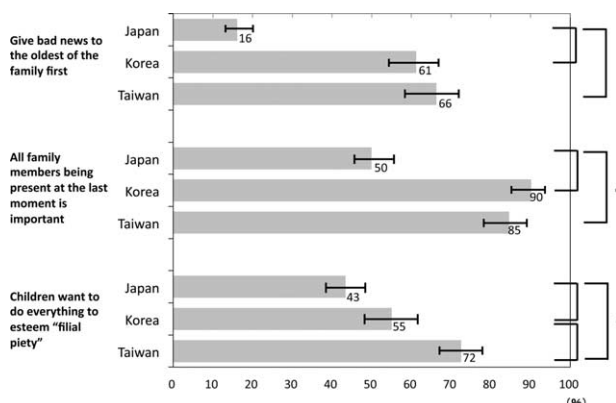


FIGURE 2. Role of family members. * $P < 0.01$; bars demonstrate 95% confidence intervals.

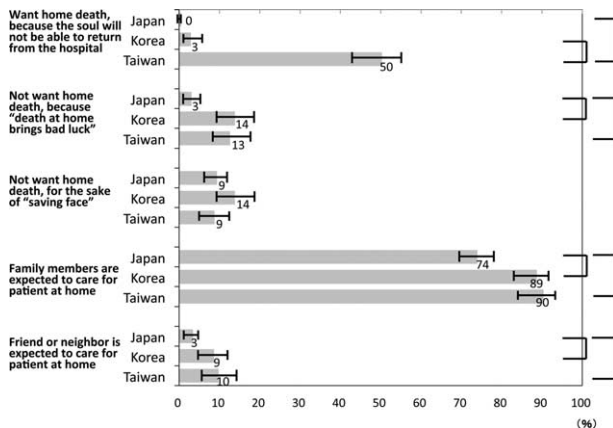


FIGURE 3. Home death. * $P < 0.01$; bars demonstrate 95% confidence intervals.

soul would not be able to return from the hospital; while less than 5% in the other countries had a similar experience (Figure 3). There were no marked differences among the countries in the remaining items: less than 15% of physicians in all 3 countries stated they often or very often experienced "death at home brings bad luck" and "saving face" as reasons to avoid home death. In all countries, more than 70% of the physicians reported they often or very often found that certain family members were expected to care for the patient at home, but 10% or less found that friends and neighbors were expected to help in this regard.

Circumstance Surrounding Death

At the time of death, a smaller number of Japanese physicians than Korean or Taiwanese reported that they often or very often experienced patients wanted a religious person to visit them (Figure 4). There were no marked differences among the countries in the remaining items: less than 15% of physicians in all 3 countries stated they often or very often experienced "death at home brings bad luck" and "saving face" as reasons to avoid home death. In all countries, more than 70% of the physicians reported they often or very often found that certain family members were expected to care for the patient at home, but 10% or less found that friends and neighbors were expected to help in this regard.

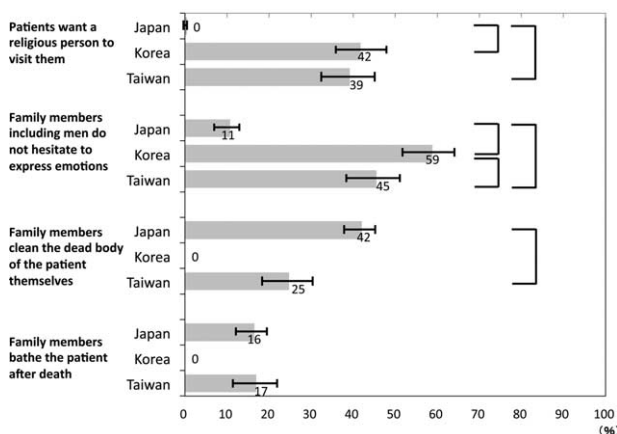


FIGURE 4. Circumstances surrounding death. * $P < 0.01$; bars demonstrate 95% confidence intervals.

DISCUSSION

This is the first cross-cultural study investigating common beliefs and practices when death is approaching in East Asian countries. The clinical implication for a worldwide audience is that this study clarified some important points every clinician should pay attention to in caring for dying patients, from the East Asian perspective. The research implication is that the items investigated in this study can be used in further international surveys of other ethnic populations. Through more studies on multicultural populations worldwide, we can gain insight into what is usual in terms of beliefs and practices when people die.

This study revealed that Confucianism has a strong influence on behaviors when people die in Korea and Taiwan, but not in Japan. Confucian philosophy emphasizes family values and respect for the oldest person. Filial piety is a virtue of respect for parents, and is central to Confucian role ethics.⁴ In an end-of-life context, filial piety means to take care of the parents and do everything good for the parents. In this study, all items investigating family roles were rated higher in Korea and Taiwan, that is, physicians give bad news to the oldest or head of the family first, all family members are present at the last moment, and sons/daughters want to do everything they can to esteem filial piety. In Korea and Taiwan, dying and death is perceived not as a personal issue, but rather as a family issue. This study suggests that the Japanese situation seems to be a little different, consistent with some observations.^{4,20} Japan is moving to put more focus on the individual in the modern period, and the role of the family is not as pronounced as in other East Asian countries.

The role of religion is a focus in cross-cultural studies. This study highlights the lack of participation of religious persons in the dying process in Japan, in contrast to Korea and Taiwan. Japanese generally identify themselves as Buddhist and Shinto, but many do not actively participate in religious activities.⁴ In contrast, 40% of Koreans identifies themselves as Buddhists or Christians; Korea is an Asian country with a large Christian population. Many Taiwanese identify themselves as Buddhist and Taoist, and frequently visit temples to pray as a part of daily life.⁴ This finding is in contrast to the situation in Japan, where palliative care clinicians regard religion as less important for a good death, and there are difficulties in obtaining a clear consensus about what spiritual care is and how spiritual care should be provided in Japan.²² Moreover, in this survey, Japanese family members were reported to be less expressive of emotions at the time of death, as they believe silence is a preferable attitude at sad events. This finding is in contrast with the Korean and Taiwanese attitude, in which honestly revealed emotion is an expression of respect for the deceased.^{4,25} Clinicians should note that the extent to which family members express emotion at the time of death depends on the cultural norms of the society and varies culture to culture.

In addition to the effects of Confucianism, each country has cultural issues unique to that country. In Taiwan, people want to die at home because they believe the soul would not be able to return from the hospital if the patient dies in the hospital. This belief leads to a phenomenon of discharge just before death: Taiwanese sometimes go back home just before death even if the patient is unconscious, and this is legal in Taiwan.⁴ An international meta-analysis revealed factors associated with death at home, but such beliefs were not investigated.²⁶ This finding suggests that, in some countries, death at home is not a medical issue alone, but rather a cultural one. Also, cleaning the dead body of the patient by family members themselves is a

Japanese tradition. Domestic nationwide surveys revealed that some inpatient hospices in Japan include bathing the patient after death as part of their usual care, but 40% of families cleaned the dead body of the patient by themselves.^{27,28}

With regard to traditional reasons to avoid home death, that is, “death at home brings bad luck” and “saving face,” there were no marked differences among the three countries. Also, there were no differences in who were the expected caregivers at home: in these 3 countries, those expected to be caregivers at home were the family; friends, or neighbors were rarely expected to be informal caregivers at home. Although saving face or *sekentei* has been listed as main reason families in Japan do not have professional caregivers,⁴ we found this value is consistent in the East Asian countries investigated. Unlike some countries, such as in Latin America, where friends or neighbors are acknowledged as informal caregivers at home, the East Asian situation puts a strong emphasis on family.^{1,2,4}

Reluctance to participate in end-of-life discussions is a common practice all over the world, especially in Asia.⁴ The most hypothesized interpretation is that Confucianism does not systemically refer to life after death, and death has been a taboo for long periods.⁴ This study examined 2 specific reasons for the unwillingness to take part in end-of-life discussions, that is, “bad things happen after you say them out loud” and “a bad life is better than a good death.” These are traditional views, especially frequently observed in Taiwan, and more frequently in Taiwan than in Korea and Japan. Taiwan is the first county to enact a Natural Death Act,^{20–22} but palliative care clinicians in this study reported they experienced more reluctance among patients and families in Taiwan to discuss end-of-life issues than in Korea and Japan. This might lead to professional and ethical conflicts or dilemmas among Taiwanese healthcare professionals,^{20–22} and further follow-up study on changes in public attitudes about end-of-life discussions in East Asia is needed.

This study has several limitations. First, the response rate in Taiwan was low, and, in Korea, there was no registry of the subjects to be studied. Recruitment process including payment was also different among the countries. Therefore, there may be a considerable nonresponse and selection bias. Second, the measurement instruments were not formally validated. Nevertheless, we believe that this is an acceptable limitation, because there are no standardized measurement tools for our study aims and the results obtained in the study are highly interpretable. Third, this study investigated physicians’ views only, which might be different from actual observations of patients and families. Future studies should include direct observation of the behaviors of patients and families when death is approaching. Finally, this study did not explore the potential influences if sociodemographic factors such as education and economic status and outcomes were measured. This might be addressed in future studies.

In conclusion, there are significant intercountry differences in beliefs and behaviors when death is approaching in East Asia. Palliative care should be provided in a culturally acceptable manner for each country. Future studies on direct observations of patients and families are needed.

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